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Biographical value: towards a conceptualisation of the ‘commodification’ of illness narratives in contemporary health care

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ABSTRACT

Illness narratives play a central role in social studies of health and illness, serving as both a key theoretical focus and a popular research method. Despite this, relatively little work has gone into conceptualising how and why illness narratives – be they in books, websites, television or other media – are ‘commodified’ in contemporary health care and its social environment: namely, how distinctive forms of ‘value’ are generated in the production, circulation, use and exchange of illness narratives. In this paper we propose the notion of ‘biographical value’ as a first step towards conceptualising the values attributed to illness narratives in this context. Based on a secondary analysis of thirty-seven interviews with people affected by fifteen different health conditions in the UK (all of whom have shared their illness experiences across various media), and drawing on understandings of ‘value’ in research on the bioeconomy, and the concept of ‘biovalue’ in particular, we sketch out how epistemic, ethical and economic forms of value converge and co-constitute each other in the notion of ‘biographical value’ and in broader economies of illness experiences.

INTRODUCTION

Collecting and analysing stories about people's experiences of illness are major activities in medical sociology, where the 'illness narrative' serves as a key theoretical focus (Hydén 1997; Bury 2001; Frank 2010) and a popular research method (Riessman 1993; Hurwitz et al. 2004; Thomas 2010). In spite of this, relatively little sociological attention has been applied to examining the political, economic and ethical dynamics at play in what we, tentatively, refer to as the 'commodification' of illness experiences. By the latter we mean the rise of different and overlapping 'markets' in which illness narratives are produced, circulated, used and exchanged, generating 'value' in different ways for different people. Key examples of such 'commodification' are: the growing market for autobiographies about people's experiences of illness (dubbed autopathographies (Aronson 2000) or, somewhat disparagingly, 'sick lit' and 'misery memoirs'); the prolific sharing of information about illness experiences on social media; the deployment of patient stories by health charities and other organisations for fundraising; and the collection, analysis and quantification of patient experiences by academic researchers for a variety of reasons, such as measuring the quality of health care services.

In this paper, we focus on one dimension of the 'commodification' of illness narratives – that of patients' perceptions of the 'value' generated when they share their experiences of illness. We recognise that the notion of 'value' is extremely ambiguous, emerging differently in different situated, culturally informed, 'regimes of value' (Appadurai 1986). Therefore, we do not seek to define or measure the 'use' or 'exchange' value of illness narratives as they are produced, collected, shared, marketed or sold; nor do we conduct a political economy style analysis of how illness narratives are turned into commodities in relation to a particular condition (as has been, for example, undertaken with breast cancer (King 2008)). Instead,

drawing on a secondary analysis of interviews with thirty-seven people affected by fifteen health conditions in the UK, we use patients' self-reported reasons for why they share their illness experiences as a foundation for conceptualising value generated by the production and circulation of illness narratives. The concept of 'biographical value', which emerged from this process, was developed through comparing and contrasting the themes arising from our secondary analysis with existing literature on illness narratives, health social movements and biopolitics. In particular, we have drawn on research on the 'bioeconomy' and the notion of 'biovalue' (Waldby 2000; 2002; Waldby and Mitchell 2006; 2010), which serves as both inspiration and counterpoint for that of 'biographical value'.

In the next section we provide a brief overview of key literature that informed our thinking. Although presented up-front as necessary background to the concept of 'biographical value', this should be read as being in dialogue with the subsequent empirical analysis, rather than as preceding it. Our findings are presented in three empirical sections, each of which serves a building block in the development of the concept of 'biographical value'. First we outline how the location of illness narratives in someone's *embodied*, lived, experience, is crucial for how value is generated from them. Second, we suggest that *whose* experience the story relates to adds a vital dimension, with the experiences of well-known public figures being particularly privileged. Third, we argue that the value generated from sharing illness experiences is *simultaneously* ethical and economic. Finally, we bring these three elements together and situate the concept of 'biographical value' in relation to how 'biography' has been typically understood in the sociology of health and illness.

THINKING ABOUT VALUE: ILLNESS NARRATIVES IN COMMODITY

SITUATIONS

In medical sociology, illness narratives (stories about experiences of illness) have usually been studied in one of two ways. In the first, as exemplified by the influential work of Arthur Frank (Frank 1995; 2004; 2010), the emphasis is placed on unwrapping *how* illness is represented and communicated through different narrative forms. While this work draws attention to the complex and socially contingent nature of illness narratives, it focuses on narrative structure rather than broader socio-political factors. In the second, narrative methods (primarily the qualitative interview) are used as a means of better understanding *what* people affected by different health conditions experience (for a review see Lawton (2003)). This latter work has informed our understanding of how people experience, live with and cope with numerous conditions, but has been criticised for adopting an overly simplistic attitude towards patient narratives and the research interview in particular (Bury 1991; Seale 2003; Atkinson and Delamont 2006; Thomas 2010); often ignoring the significant contextual factors (power dynamics, motivations, audience, timing etc.) at play in the sharing of illness experiences (for a review see Hydén (1997)).

While the extant literature on illness narratives enhances our understanding of how people articulate their experiences of health and illness, it does not provide the necessary theoretical toolbox for exploring the processes whereby illness narratives are turned into ‘commodities’.

A ‘commodity’ is generally defined as an object that has some *value*, can be used or exchanged, and is often, although by no means always, sold for money (Parry 2008).

However, as Appadurai has argued, commodities do not simply *exist* as definable objects, but should be understood as things in ‘*commodity situations*’, in which the exchangeability of a ‘thing’ becomes a socially relevant feature (Appadurai 1986, p.13). This means that further

analysis is needed to elucidate the situations, and the consequences of those situations, in which illness narratives *become* commodities. In order to do so we draw on theoretical resources from a field that might at first seem rather removed from that of illness narratives – sociological analysis of the bioeconomy.

Over the last decade there has been growing sociological and anthropological interest in how ‘bodily fragments’ (blood, organs, and other tissue) can, with increasing ease, be separated from their original host, altered, redistributed, and reincorporated in complex economies (Waldby 2002). This has resulted in the analysis of different ‘tissue economies’ (Waldby and Mitchell 2006), such as that of organs and body parts (Scheper-Hughes & Wacquant 2002), blood (Busby 2006), umbilical cord blood (Brown 2012), and stem cells (Waldby 2002). Here, considerable attention has been given to thinking through ‘commodification’ and ‘value’ in relation to ‘bodily fragments’. One notable and frequently cited example of this is Waldby’s notion of ‘biovalue’, defined as the ‘yield of both vitality and profitability produced by the biotechnical reformulation of living processes’ (Mitchell and Waldby 2010, p.5).

While we are not interested in ‘bodily’ fragments here, the concept of biovalue provides a useful point of departure for conceptualising the generation of the value(s) we are interested in – those tied to the constitution and circulation of illness narratives and to the creation of economies of *biographical*, rather than bodily, fragments. Two aspects of biovalue, in particular, informed our development of ‘biographical value’. The first is the role of different logics of separability in how ‘vitality’ and ‘profitability’ are produced from bio-samples. The second is the way in which economic value and ethical value co-constitute each other in the

concept of biovalue (for a critique of this see Birch and Tyfield (2012); for a discussion of this in relation to the notion of ‘biocapital’ more generally see Helmreich (2008)).

In much of her work Waldby has stressed how the production of biovalue hinges on processes whereby biological samples are *separated* from their original hosts and associated clinical labour:

The economic value of the cell line [for example], moreover, has (at least in the United States) been deemed dependent on the *absence* of any link to its ‘idiomatic’ origin in a particular individual. It is only when a tissue sample is legally separated from the donor through the informed consent process, deemed no longer ‘his’ or ‘hers,’ that it becomes biovaluable, able to be anonymized, technically altered, and claimed as the intellectual property of the scientist or corporation. (Mitchell and Waldby 2010, p.5)

However, Mitchell and Waldby have argued that in some contexts, such as in national biobanking, an inversion to this logic of separability is required in order to create *new* forms of value – in this case the discovery of disease risk factors (Mitchell and Waldby 2010, p.5). In such cases, it is precisely through maintaining the connection between a biological sample (or data set) and a *particular* individual or group that value, economic or otherwise, is produced. Thus, questions around embodiment and disembodiment, entanglement and separation, the alienable and the inalienable, are crucial for understanding how different parts of the human body are turned into commodities which circulate in different, constantly changing, geographically dispersed, regimes of value (Lock 2001; Parry 2008).

In a similar vein, in our own analysis, the value that people living with different health conditions attributed to their own and others’ illness narratives was tied up with the ways in

which these stories were *both* inseparable and separable from the life histories, demographics, and characteristics of particular individuals or groups to whom the story related. Indeed, it is hard to talk about the value produced through illness narratives without linking it to *specific* individuals and conditions. Yet, these narratives, at the same time, need to be separated out, re-packaged, distributed and re-incorporated in different contexts in order for value to be generated from them. And it is precisely through maintaining both a connection with a particular individual and separating out their experiences into a packaged, distributable form (such as in an autobiography or a blog post) that illness narratives become commodities.

Much social theorising on the bioeconomy draws on Titmuss's classic comparative study of the blood donation systems in the UK and US (Titmuss 1997 [1971]). Here, Titmuss argued in favour of a 'gift' (altruistic) economy for blood donation rather than a 'commodity' (profit-based) one. Such a system, he posited, not only created positive social relations but resulted in a better blood supply for those that needed it. This clear demarcation between 'gift' and 'commodity' economies has been challenged and it is now recognised that these two modes of exchange are considerably blurred in contemporary tissue economies (Waldby and Mitchell 2006; Parry 2008). Similarly, a fundamental feature of biovalue is the way in which particular ethical valuations form part of the calculation of economic, often as yet unrealised, potential value of biological tissue (Birch and Tyfield 2012).

While conducting our secondary analysis, we found that when people spoke of the benefits they and others accrued from sharing their illness experiences, ethics and economics were similarly blurred, often co-constituting each other. Thus, rather than conceptualising the 'value' generated from the circulation of illness narratives as either altruistic ('gifts') or

financial ('commodities'), our concept of 'biographical value' is understood as combining both (differently in different situations).

METHODS

This paper is based on a secondary analysis of interviews from University of Oxford, Health Experiences Research Group (www.herg.org.uk). The methods used to collect and conduct these interviews have been discussed in some depth elsewhere (Herxheimer et al. 2000; McPherson and Ziebland 2006). In brief, they are in-depth open-ended interviews lasting one hour and upwards in which interviewees are prompted to talk freely about their experiences of a given health condition. The interviews are transcribed verbatim, analysed, summarised and made available on a publicly accessible website on patients' experiences (www.healthtalkonline.org). All the interviews took place in the United Kingdom and ethical approval was granted by the Eastern Multi-Centre Research Ethics Committee (including for secondary data sharing and analysis).

The secondary analysis presented here emerged out of a broader 'supra-analysis', in which existing data is analysed from new theoretical perspectives (Heaton 2004). The initial aim of the analysis was to explore how people affected by different conditions sought out and shared their illness experiences in order to inform a broader National Institute for Health Research (NIHR) funded programme of work. Whilst analysing 124 interviews with people (patients and carers) affected by four neurodegenerative conditions: dementia, motor neurone disease (MND), Parkinson's disease (PD) and multiple sclerosis (MS), we identified a number of occasions where interviewees discussed *why* they had chosen to share their experiences. This resulted in emergent themes focused on the 'motivations for' and 'perceived consequences'

of sharing illness experiences. In order to explore these themes further we extended our sample to include interviews conducted with people affected by different health conditions.

As the Health Experiences Research Group archive is made up of almost three thousand interviews covering over seventy conditions it was not possible to do an exhaustive analysis of all available interviews. Moreover, rather than a representative sample of conditions, we wanted a strategic sample of participants who had been both active in sharing their experiences (i.e. had written books, had a blog, etc.) and had reflected on this in their interview. To facilitate our selection process authors one and two (who is very familiar with the archive and was a primary researcher for some of the interviews) had informal discussions with primary researchers in the group to get their advice on interviews they had conducted, or were aware of, where participants had spoken of how and why they shared their experiences. A number of interviews were suggested and these were included and analysed.

While this significantly extended and enriched our existing analysis, new themes were still emerging, so we continued to add interviews until data saturation was reached (both in terms of the emergent themes and the types of medium through which interviewees had shared their experiences). In order to select which interviews to add FM looked through the summaries provided on the Health Talk Online website. These summaries are based on previous analyses conducted on the interviews and are structured according to key themes. A number of themes – ‘telling other people’, ‘information’, ‘sources of support’ and ‘messages to others’ (depending on the condition these can be marked by similar phrases) – focused on topics relating to sharing experiences. These themes were used to help narrow down our selection process. For example, if under the theme ‘telling other people’ there was a quote where an

interviewee spoke of how they had written about their experiences in a magazine that interview was retrieved and analysed in its entirety.

As our existing sample already included interviews relating to certain conditions (i.e. neurodegenerative diseases and mental health conditions), we focused on online modules for which we did not as yet have any interviews (i.e. cancer and musculoskeletal diseases). Internet technologies and social media had emerged as key mediums for sharing experiences and we prioritised interviews conducted after 2005 to ensure we included information on this (our sample already included a number of interviews conducted prior to 2005).

Once an interview was selected it was analysed in its entirety. Constant comparison coding was conducted across the corpus of interviews with a particular emphasis on ‘motivations for’ and ‘perceived consequences’ of sharing illness experiences. When new themes stopped emerging and it was deemed that data saturation had been reached no new interviews were added. This resulted in a total of thirty-seven interviews across the following fifteen conditions: Alzheimer’s disease (1); Autism spectrum disorders (2); cervical intraepithelial neoplasia 3 (CIN 3) (6); Colorectal cancer (2); HIV (2); Leukaemia (1); ethnic minority experiences of mental health (2); organ donation (1); osteoporosis (5); pancreatic cancer (1); psychosis (2); rheumatoid arthritis (2); testicular cancer (1); Parkinson’s disease (7); MND (2) – sixteen men and twenty-one women.

All the interviewees who took part in the original research knew that text, audio and/or video clips of their interviews would be made available on a publically accessible website with the specific aim of providing information about patients’ experiences to other patients. In addition to taking part in the research interview, interviewees had shared their experiences

across a variety of other media. Face-to-face and online community support groups were frequently discussed. Some interviewees kept blogs, contributed to websites (either their own or ones owned by other organisations such as health charities), spoke at public events, wrote articles and/or books, or had taken part in televised documentaries or discussion programmes.

A significant portion of what we found related to the emotional and therapeutic benefits of peer-support, a topic already much discussed in sociology and psychology (Borkman 1976; Winefield 2006; Bar-Lev 2008; Locock and Brown 2010; France et al. 2011). Interviewees also expressed awareness, in some cases with a great deal of reflexivity and strategic intent, of the political and economic dimensions of sharing their experiences. While the production and distribution of illness narratives were not spoken of as part of a ‘market’ in the straightforward sense of them being commodities exchanged for money, the illness ‘experience’ was seen as having the potential to generate particular types of *value* through processes of articulation and commodification. For the remainder of the paper we turn our attention to fleshing out the value or, as becomes clearer as the paper progresses, the values, patients perceived as accruing from sharing experiences of illness in various narrative forms.

WAYS OF KNOWING: EXPERIENCE AS A SOURCE AND TYPE OF KNOWLEDGE

A key theme permeating the interviews we analysed was that in order for ‘value’ to be generated from illness narratives they had to be based on the *actual* experiences of *real* people. This may sound rather obvious, but it is a crucial point well illustrated by the public outrage that exploded when it was revealed that James Frey’s bestselling memoir about his experiences of recovering from alcohol and drug addiction, *A Million Little Pieces*, was to a large extent fictional.¹ While many interviewees mentioned how autobiographies of other

people's illness experiences informed how they understood and coped with their own condition, fictional accounts were not spoken of in the same way.

In terms of sharing their own experiences, interviewees frequently stated that their illness narratives were valuable because they were based on *real* experiences. Furthermore, interviewees not only differentiated illness narratives from fictional and/or sensationalist accounts, but also from 'disembodied' medical knowledge. One man who had colorectal cancer and subsequently worked as a volunteer helping new patients learn how to manage a colostomy at home, explained it as follows:

They've [hospital staff and stoma care nurses] got a bit of learning from books but it ain't nothing like living with it. It really is quite a different thing and all their ideas really as I say are book learning which I don't know who writes the books but they haven't had one [colostomy] either if you know what I mean. And when you live with one you learn that it can be quite capricious at times and it can do all sorts of things, odd things that you can't expect or you don't expect and really and truthfully the best thing is to find somebody who's got one.

(Interview 11, colorectal cancer)

In this example the interviewee draws attention to how living with a colostomy confers a special type of knowledge that, no matter how well read or trained you are, you simply cannot achieve unless you have actually lived with one. Here, the interviewee directly contrasts his experience of 'living with it' and the 'book learning' of healthcare practitioners, invoking the embodied source of his knowledge as a crucial justification for why his experiences are of value to other patients. There are two dimensions to this: first, as someone who has personally experienced a colostomy he knows about it in a very particular way;

second, this experiential way of knowing enables insights that people who have never had a colostomy simply do not have.

This emphasis on ‘embodiment’ is echoed in the academic literature on patient expertise and ‘experiential knowledge’, in which forms of knowledge accrued through ‘bodily’ and ‘lived’ experience have been highlighted as a key area of knowledge that patients can lay claim to (Abel and Browner 1998; Prior 2003). Indeed, it is partly because experience is deemed to be a valuable and distinctive source of knowledge that many social scientists interview patients (Atkinson and Silverman 1997; Atkinson and Delamont 2006). In the interviews we analysed, experience was usually framed as a supplement to, rather than a replacement for, other sources of knowledge, such as biomedical ones, although in some cases, such as the quotation above, the epistemic value of experience was particularly privileged.

In addition to highlighting how personal experience is a particular way of knowing and a valuable source of knowledge, participants frequently stressed that only people who had gone through the *same* experience as them could understand and provide the right kind of information and support:

[W]hen you get cancer you join a club that only the other members of that club can understand. Only people who’ve had bowel cancer particularly can understand how other people with bowel cancer feel. Yes, people with cancer, we’ve all got common experiences, but bowel cancer’s different. (Interview 10, colorectal cancer)

I needed to speak to other people in similar situations. I mean the doctor could be sympathetic but if they’ve not been through it, they don’t know what I’m going through. I mean they can understand but they don’t really get what I was going through. (Interview 5, CIN 3)

In the above two quotations it is not simply the value of experience as embodied knowledge that is emphasised, but the *shared* experience that underlies this. Indeed, a sense of affiliation and shared understanding are frequently cited as important aspects of peer-support (Ussher et al. 2006; Locock and Brown 2010).

Many interviewees said they believed their experiences had the potential to be useful to others because *they* had been both practically and emotionally helped by others' experiences. Hence, rather recursively, personal experience was used to validate the value of sharing one's own experience. This included taking part in the interviews we analysed, which interviewees knew would be made available to other patients on a public website as well as used in academic research and medical education:

The help given to me by medical practitioners by my doctor, by all of the people that were around and available to try and give me help and support was fantastic. But really at the end of the day what works for me is listening to somebody's experience who has been through this and who can say, you know, 'I was like this and what helped me was doing this. Or the things that I found worked for me... do you know, I tried that, it didn't work for me, but I wouldn't discount it, give it a try. Maybe it will work for you.' It is that kind of thing that I think is most useful.

So it is important to hear people's experiences and their stories about...?

Massively, that is exactly why I am doing this now. (Interview 13, HIV)

The value of experience is not, therefore, simply based on its status as embodied knowledge, but emerges out of the enactment of a shared embodiment of a particular condition. While a distinction has been made between ‘embodied’ knowledge (knowledge produced through one’s own bodily experience) and ‘empathetic’ knowledge (knowledge produced through caring for someone else) (Abel and Browner 1998), in the case of patients sharing their experiences with others who have the same condition the lines between the two become blurred (Mazanderani et al. 2012).

THE DIFFERENTIAL EFFECT OF ILLNESS NARRATIVES

While interviewees spoke of everyone’s experiences as having the potential to be of value, they were highly reflexive about how (their own and others’) demographics, social position and personal characteristics influenced the impact their illness narratives had on others and the broader field of health care. Some interviewees drew attention to how the unusual, distinguishing characteristics of their experience or profile made it especially important for them to share their experience, while others perceived their ‘typicality’ or ‘normality’ as an equally important motivation for sharing theirs. In three of the Parkinson’s disease interviews, for instance, the fact that the interviewees were comparatively young was given as a reason for them to share their experiences, raise awareness and be actively involved in Parkinson’s disease organisations. In these cases, they felt their youth increased the value of them sharing their experiences as it counterbalanced the perception that Parkinson’s only affected ‘old’ people and provided support for ‘young’ people who they believed were not fully represented in the Parkinson’s disease community. In contrast, in a number of the CIN 3 interviews, women stressed how it was necessary for ‘normal’ women to share their experiences to make others aware that it could happen to anyone.

In addition to highlighting specific characteristics and demographics (such as age, gender, ethnicity) as a means of differentiating (and in some cases justifying) sharing their own illness experience, interviewees spoke about the *relative* ‘value’ of different people’s illness narratives. This was particularly noticeable in discussions on celebrities affected by illness, and in almost every condition analysed at least one public figure with the condition in question was mentioned. For example, in the CIN 3 interviews, conducted after Jade Goody’s diagnosis with cervical cancer, references to the reality TV star were common:

I mean the first thing that I even thought about cervical cancer was Jade Goody. And she’s, to be honest, she’s probably the only person, the one person that’s made everybody aware of it. You know, and then obviously looking into that, and then you see how it develops and reading her story and obviously she went through the same stages as what a lot of other women have done. (Interview 5, CIN 3)

But Jade Goody was diagnosed in August and my diagnosis was in September. And part of the reason I went with the bleeding is because obviously it was in the media, and it was something that was brought to an awareness. (Interview 6, CIN 3)

However, rather than interviewees simply being aware of celebrities with the same condition as them, and in some cases buying celebrities’ books (e.g. Michael J. Fox’s *Lucky Man: A Memoir*), they reflected on how the association of an illness with *a particular* person impacted on public perceptions of that condition. For example, in the MND interviews this was discussed in relation to the British astrophysicist Stephen Hawking’s unusual longevity, both as a source of hope and as a misleading anomaly:

In the United States there is more public awareness because it is well-publicised and was given another name of Lou Gehrig's Disease after the sportsman of that name died of it. In this country, despite the fact that Professor Stephen Hawking is of interest to the media, I wonder if his unusually long life gives the public an incorrect perception of the disease.

(Interview 37, MND)

Furthermore, interviewees spoke of how when someone famous was affected by a disease they could have a particularly powerful impact on its profile as well as funding and research:

[...] What we really need is a big time celebrity to get it [Parkinson's disease]. I know that sounds horrible but Jane Asher is the president at the moment of the Parkinson's disease society and her brother-in-law, Gerald Scarfe's her husband, and his brother has Parkinson's disease. And she's helped the profile, but, you know, Michael J Fox in America has set up this huge foundation to research. (Interview 34, Parkinson's disease)

Two of the interviews we analysed were conducted with people who were well-known public figures prior to their diagnosis, one a TV presenter and the other a successful author. Both spoke about how their status as public figures enabled them to use their illness experiences in various ways that made a positive impact on other people affected by the condition in question. Below the latter speaks of how he uses his public profile to raise awareness of Alzheimer's:

Because people say to me, you know, 'Do you mind talking about your Alzheimer's?' I say, 'I stood up there in front of a load of people and said I'd got it. In fact, I put it on the internet. I want to talk about it.' It's because we don't talk about the dragon that it never gets slayed. I'd like to think that since I did that and since other people, some unsung, unsung heroes that I know don't get the same publicity as me, have made some kind of a change [...] Then the

more we will think about it the more we will be generous, be generous in how we think about those who have it and the more we will press to make certain it doesn't happen to us.

(Interview 1, Alzheimer's)

In this passage, the positive effects of 'talking about' Alzheimer's – increased empathy for people living with the condition, working towards better prevention, treatment and a cure – are amplified by the interviewee's public status. However, it is also important that the identification of a 'celebrity' with a condition shapes both the latter's own public image and the public construction of the condition they are associated with. This mutual constitution is aptly illustrated by the quotation below, in which a young man with a mental health condition speaks of how he is inspired by other people's experiences and wants to inspire others with his own:

[W]hat I draw a lot of inspiration from is the people that have experienced mental health difficulties and have gone on to do well. You know, like if you look back at history, you know, Winston Churchill had mental health, he had very bad depression, Abraham Lincoln, one of the greatest presidents of America, he had mental health difficulties, so I think that, you know, mental health difficulties people experience in their life but they can do well, they can make an enormous contribution to society and I tend to look at it in a very positive way, because if you started looking at it negatively what, what will people think of you? And, and I tend to think positive of life and I tend to think, 'Look, this was an experience I had, and it's one that will live with me', but I want to now, if I can, inspire other patients and also help them at the same time. (Interview 15, ethnic minorities' experience of mental health)

CONSTITUTING VALUES: ETHICS AND ECONOMICS

In keeping with the pursuit of health as a key virtue in ‘advanced liberal societies’ (Rose 2007, p.11), interviewees spoke of sharing their experiences of illness as part of, to paraphrase Foucault, ‘care of the self’ – an ethical process of self-transformation and fashioning in the context of living with their particular condition (Foucault 1990). For example, the woman in the quotation below spoke of how writing her memoir played an important role in helping her accept her mental health problems and promote a sense of well-being:

My writing, I mean, has been the reason I’ve, you know, stayed alive so long, and it’s also now, proving to be a, a, it is not just a means of survival or expression, it’s now a career, actually, which is really good. And the hardest book to write was my memoir about my life, but it also changed my perception of myself in that once I read – I wrote my story of my life between 0 and 30 and I hated myself, you know, as I wrote it. Because it was, you know, so horrible. But after re-reading it I had empathy for myself. You know, I could understand that, you know, I wasn’t a bad person, but I am a person who can love and be loved, you know. So it, it does, it empowers you in that really kind of, you know, strange way, that you have empathy for yourself. (Interview 16, ethnic minorities’ experience of mental health)

While the woman in question felt that writing about her experiences played an important role in improving her own health, combatting stigma, and raising awareness about mental health problems, this was also, crucially, about creating a ‘career’:

I’m very open. In fact I kind of ... I call myself a mad ambassador. So I do a lot of media work. I write about my experiences. I mean, I’ve had a couple of books published about my experience by [publisher name]. So I also do kind of public awareness. So I’ve spoken to

police, I've spoken to school kids. (Interview 16, ethnic minorities' experience of mental health)

Here, as in many other cases, the interviewee claimed that in sharing her experiences she was not only improving her own wellbeing but that of others. It is precisely this tight coupling – helping oneself through helping others, helping others through helping oneself – that makes sharing experiences such a powerful form of self-care – helping others *is* helping oneself. Thus, the 'value' of sharing one's experience in this context acquires a strongly ethical dimension, the ethical 'subject' (Foucault 1982) here being both the person doing the sharing and their perceived or actual audience(s). And while the effect of sharing experiences might differ, an intention to help those already affected by a condition is key:

There's a whole community whose experiences are only just being recognised and registered. And to me some of the basic things is just getting those voices, not stored, but there, so that you grow a history [...] And it will bind me to people who have similar experiences to others. It's a courageous thing to do and it's a dignified thing to do and sometimes it's all you've got. And it's really, really precious. No one can take your voice away from you, but they can silence it. (Interview 25, psychosis)

In addition to those directly affected by a particular condition, interviewees mentioned many other ethical 'subject(s)' of experiential information sharing. The most prominent of these were healthcare practitioners and policy makers, the general public and people who *might* potentially be affected, for example, in the quotation below, women who fail to go for regular smear tests:

I never used to talk about smears before. I tell everybody now, because I want them either to tell somebody else that they know somebody who's been through something similar to help them if they need to go through it. Or to spur on people to go for their smear on, I think last time, I'm on Facebook and I put on, 'Having to wait for my results.' And someone had contacted me who I used to work with, saying, 'Oh what results are you waiting for?' I told her everything, and she said, 'Oh I wasn't going to go for my smear. I think I will now.'

(Interview 7, CIN 3)

While 'helping others' was articulated as a direct outcome of sharing illness experiences, this was not the only 'good' generated through illness narratives. Like the woman quoted in the opening of this section (interview 16), many interviewees were aware that sharing their experiences could also be a vehicle for raising money:

I have also been a member of Arthritis Research as well and did do quite a bit of fundraising in [place name] for the research of arthritis, helping with that, to actually prevent, you know, arthritis itself, so I have been interested in their magazines as well because can find out what they're doing for the future and what all the new drugs are. (Interview 26, rheumatoid arthritis)

It is important to note, however, that sharing experiences was never mentioned straightforwardly as a means of raising money for personal gain. From the perspectives of the patients whose interviews we analysed, illness narratives were produced to help support charitable organisations, buy medical equipment for a hospital or clinic, or contribute towards the financing of biomedical research. The economic value generated through sharing illness narratives was thus intrinsically tied to ethical values, as concisely articulated in the excerpt below:

I go out and I meet people and then win them over and tell them my story and go away feeling happy. And, and that's how I'd describe my NOS [National Osteoporosis Society] work. And in the meantime it raises money and it raises awareness. So ... it's a win/win. So that's the therapy, that's my therapy if you like. (Interview 18, osteoporosis)

CONCLUSION

We started this paper by stating that more attention needs to be given to analysing the 'commodification' of illness narratives in contemporary health care. Our contribution to this has been to explore how people who have actively shared their experiences of different health conditions conceptualise the 'value' of their illness narratives. We have sketched out three dimensions of this value and group them together as the constituents of what we have termed 'biographical value'.

First, for someone's 'illness narrative' to generate value (for them and/or others) it needs to be seen as referring to *a* person's 'experience', understood as a distinct – *embodied* and hence *authentic* – source of knowledge. Furthermore, the value generated by sharing experiences operates on both an individual and a communal level with the enactment of a *shared* experience of a particular condition being an important element of *how* value is generated from sharing experiences and an *outcome* of these sharing practices. Thus, being exposed to and helped by others' experiences motivates patients to share their own, contributing to the body of knowledge about a disease.

Second, the perceived value of an individual's experience is tied *differentially* to the way in which that individual is situated in broader socio-political and cultural contexts. In interviews, this differential was discussed as being based on people's respective demographics, on how 'unusual' or 'typical' or of how much interest to the 'public' they

were. Illness narratives produced about or by celebrities were deemed as having the most effect in terms of raising general awareness, fundraising and research.

Third, a primary aim of experiential information sharing is that sharing illness experiences will help others in some way – the value generated from illness narratives is of a distinctly ethical nature. In cases where tangible economic value is also generated – for example, through fundraising activities, advertising on websites or selling books – rather than being an end in itself, this economic value was seen very much as part of a broader ethical project. In biographical value, as in biovalue, economics and ethics co-constitute each other. Thus, illness narratives do not fit easily into either the gift or commodity economy models, but combine elements of both in different that are contingent on the context and condition in question.

Since Bury's seminal paper 'Chronic illness as biographical disruption', the notion of biography has been used extensively and rather loosely in the sociology of chronic illness (Bury 1982). For Bury, and others who have applied the concept in different empirical cases, biography is typically treated as an aggregate construction connected to identity, life expectations and perceptions of a past and future self (Charmaz 1983; Williams 1984; Carricaburu and Pierret 1995; Williams 2000; Locock et al. 2009). In a related vein, Corbin and Strauss described 'biographical work' as one of three lines of work (alongside 'illness work' and 'everyday life' work) that people engage in when living with chronic illness, emphasising the reciprocal relationship between illness trajectory and a person's biography (Corbin and Strauss 1985).

In proposing the concept of ‘biographical value’ we are adopting a related but distinct conceptualisation of biography as an account of the life of an individual *and* the practice of producing stories about that life (Denzin 1989, p.10). Thus, biography is, *inter alia*, the art of sharing experiences and telling stories of illness (practice and labour) and the written account or other output (video, audio recording, verbal exchange), linked, to a greater or lesser extent, to a particular person. Our decision to use the term ‘biographical value’, based on the understanding of ‘biography’ as outlined above, rather than ‘narrative’ or ‘experiential’ value is because of the way interviewees’ connected illness experiences, narratives about those experiences and the biographies of particular individuals. Here, as in the logics of separability described in relation to the generation of biovalue, the turning of illness experiences into commodities required complex processes of connecting and separating, embedding and dis-embedding, stories about illness to and from particular people and communities.

The analysis presented in this paper is based on interviews with patients. As such it is grounded in what they articulated in research interviews. Clearly, this offers a partial perspective on illness narratives in commodity situations. While economic motivations and outcomes were discussed, they formed part of a complex moral economy in which the economic value of illness narratives was both constituted by and subsumed by epistemic and ethical values. ‘Profitability’, real or imagined, sits at the heart of the concept of ‘biovalue’ (Waldby, 2002), but in the case of ‘biographical value’ questions of economic profit are dispersed, often hidden or implicit. When illness narratives did generate money this was not presented as being for personal gain. At the same time, however, interviewees recognised illness narratives as things that have value that can be gifted and/or exchanged – in other words, turned into commodities. Further work is needed to explore the specifics of how this happens in relation to different conditions and contexts in order to chart out and develop an

understanding of different 'economies of patient experiences', many of which we as social science researchers interested in health and illness depend and contribute to.

NOTES

¹ We would like to thank Rachel Hall-Clifford for bringing this case to our attention. The controversy about Frey's book took place after *The Smoking Gun* published an article titled 'A Million Little Lies' that questioned the truth of various events claimed to have taken place in the book (<http://www.thesmokinggun.com/documents/celebrity/million-little-lies>). Questions about the validity of the memoir was discussed on CNN, Larry King Live, Oprah, and in numerous articles published in newspapers and magazines. Eventually Frey's publishers requested him to write an apology to appear in later editions of the book (<http://www.randomhouse.biz/media/pdfs/AMLPO20106.pdf>).

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